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ABSTRACT

A mother and father (both deaf themselves) of one deaf and one hard of hearing child share their parenting experiences, with emphasis on effective strategies for family sharing and bonding. The father begins by sharing his experiences growing up as a deaf child of deaf parents. The mother then recounts her childhood experiences as a deaf child of hearing parents. Their reaction to discovering that their first child had a significant hearing loss and their adoption of a deaf toddler are recounted, as are difficulties with professionals over the years, coping with behavioral problems, and their children's successful college experience and adult adjustment. Advice for other parents includes treating the child as an individual, involving the child in everyday communication activities, exposing the child to all kinds of experiences, meeting and interacting with deaf adults in the community, networking with other parents of deaf and hard of hearing children, and becoming involved in the child's school. (DB)

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Parenting of Deaf Children

Growth through Communication

Family Sharing and Bonding

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Vicki T. Hurwitz

A Panel Presentation at the

International Congress on Education of the Deaf

Tel Aviv, Israel

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T. Alan Hurwitz

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

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Running head: PARENTING OF DEAF CHILDREN

It is an honor for us to be on the panel to share our experiences in parenting deaf and hard-of-hearing children. We hope that you will glean from our personal experiences, effective strategies for family sharing and bonding.

I will begin by sharing my experiences growing up as a deaf child of deaf parents. Vicki will then touch on some parts of her childhood experiences as a deaf child of hearing parents and then talk about our shared experiences in raising our two children.

Alan's Personal Experiences

I have been deaf since birth. Being a son of deaf parents provided me with the opportunity to grow up in a community where a majority of deaf people used American Sign Language as their primary language. My Mother grew up in Kansas City and received an oral education at a private school. My Father's parents were Russian immigrants and spoke very little English. They spoke Yiddish, a combination of English and Hebrew, which made it very difficult for my Father to communicate with them. His parents did not know anything about his deafness or knew of any available schools for deaf students so he stayed with his family above the family-operated grocery store until he was in his early teens. He then attended a state residential school for the deaf and completed his education at the age of 25. He passed the qualifying examination for entrance to Gallaudet College but instead, decided to get marry and find a job. My Mother did not know sign language until she married my Father at the age of 22. How they were able to communication with each other, I will never know; I guess "love is blind."

My parents knew that I was deaf shortly after I was born and because of my Mother's success with her oral education, she encouraged me to use my speech and speechreading skills. She read many books to me and made sure that I was aware of my surroundings. When I was four years old, my Mother sent me to the same private school

for the deaf that she had attended. My Father supported this wholeheartedly because he knew the benefits of a good education that he saw in my Mother. Even though my Father did not earn enough money to pay for my tuition, he was determined that I get a good education. Because my Mother was a former pupil at the school, she was able to get a partial scholarship for me. One of my uncles had offered to pay the balance of the tuition, but my parents were too proud to accept a gift of that magnitude. However, my uncle did loan the money to my parents and they paid him back after about two years after I completed my elementary education. This sacrificial act exemplified my parents willingness and determination to provide the best possible quality education for me. It was not an easy for them to send me to a private school. In fact, they were often ridiculed and criticized by deaf members of the community who felt that they were doing me an injustice by sending me to a private school. The town in which we lived was small, so it was difficult for my parents to endure these insinuations. My parents did not have anyone in the town with whom they could talk to about the aspirations they had for me. The hearing members of our family, however, were always very supportive.

I remember elementary school as being a happy time in my life. Being a residential student and living in the dormitory for ten years brought many enjoyable and interesting experiences. Living in the dorm was like have ten brothers and sisters that I didn't have at home as an only child. Although I remember my experiences as positive and happy, the food was one of the negative aspects of dormitory living that I don't cherish the thought of recalling.

After completing my elementary education, I entered the eighth grade at a regular junior high school in Iowa at the age of 13. Originally, I was prepared for entry into the ninth grade, as were my other classmates at Central Institute for the Deaf (CID), but my

Mother felt that I should repeat the eighth grade. Despite my protests, I repeated the eighth grade. The first few weeks of school were difficult for me and at times I became very depressed. I even received a "D" in physical education after the first semester and that was one of my favorite subjects! My Mother's insistence that I repeat the eight grade was a wise decision because the adjustment was arduous. There were so many new things that I had to learn. Because I could not easily read the lips of my teachers, I missed out on much information. The teachers would often speak too fast, walk all over the classroom, and would speak with their backs to the students. In those days, there were no support services. Despite the frustration, anxiety and depression that I felt, I was determined to persevere. Partly because by classmates from CID were all attending regular schools and so I was not going to go back to a residential school. My Mother was also a big influence and helped me through the transition. She remained faithful and confident in my abilities and was a constant source of encouragement.

What actually kept me going that year is still a mystery to me. I do remember my teachers and classmates being patient and kind. However, there were a few students who ridiculed me. I remember one of them pushed my head down while I was drinking from a water fountain in the hall. Surprisingly, I didn't lose my temper, I simply turned around and laughed with him. From then on... we became good friends.

Another incident happened in one of my first history classes. The teacher asked the class to recite the Gettysburg Address aloud with her. Initially I chose not to join in with the class because I was embarrassed to use my voice. But after a bit, I decided to give it a try. I became so fascinated with reciting the Address that I didn't notice that the teacher had told the class to stop in order to discuss a point. Well, I kept right on going and realized that the entire class was waiting for me to stop. I was so embarrassed at that point

that I wanted to find a hole and crawl inside and disappear. Another embarrassing incident occurred shortly afterward in the same class no less. The teacher had written a lot of historical information on the blackboard and I thought she had written something wrong. I wanted to point this out to her and so I mentioned this to her. She didn't understand me. After repeating it about four or five times, to no avail, I finally walked up to the blackboard to make the change. As I approached the blackboard, I realized that I was mistaken and that the information she had written was in fact correct. I stood motionless for a moment and gazed at the blackboard, fervently trying to figure out what had just happened. Without giving any excuse for what had just transpired, I simply walked back to my seat feeling humiliated once again and wishing that I had just kept my mouth shut. To this day, the teacher does not know what I was trying to point out to her that day. To avoid the risk of looking silly again, from that moment on, I became a very passive student.

Academically, I survived high school, but my social and extracurricular activities at the school were limited. Because of my shyness, I bypassed all school social functions with the exception of sporting events. Most of the time, I felt like a goldfish watching the outside world from inside a bowl. However, I didn't feel totally left out. I enjoyed watching my friends socialize and have a good time and I also had my family and their deaf friends to socialize with at home. Each day at home was like a retreat from the mainstream.

Vicki's Personal Experiences

My Father died serving in World War II when I was four months old. My Mother remarried when I was 3-1/2 years old to a man who knew that I was deaf. So that we could stay together as a family, we moved from Virginia to Peoria, Illinois, where I attended a self-contained classroom for hard of hearing children. Later I attended the Central Institute for the Deaf in St. Louis, Missouri. My Mother who had lived in Virginia with her family and

my step-Father, who was a New Yorker were willing to relocate even if it meant finding another job in order for us to stay together. My Mother and step-Father later had two daughters with whom I grew up with and became close to.

As I looked back on my experiences growing up, I realized that there was a turning point in my life whereby I realized that because of my deafness, I had been rejected. One night, while dining with Alan and my family, I wanted to get my Mother's attention. I proceeded to do what I had always done to get the attention of another person and that was to speak their name. I had said "Mom" several times but could not get her attention. At that point, Alan had become very agitated and banged on the table. This caught my Mother's attention immediately. It dawned on me that prior to this, it was normal for me to not know what was discussed or to be included in on conversations. I realized that my Mother was subconsciously ignoring me and was engrossed in listening to "better" things that were going on at the time. Although my Mom and others may not have intentionally ignored me, but I felt rejected. I also realized that although my parents encouraged me to do things such as dancing, Girls Scouts and B'Nia B'Rith Girls and other activities with hearing people, they in fact denied my deafness. It was my Mother who initially convinced me to get involved in these activities, but it was my Father who provided the follow through and support to make it through. Over time, I began to recall other instances where I had been ignored. What I didn't realize was that I had become a very passive person because of it; I didn't feel worthy of attention from others.

Alan and I married and started our own family. What I had gleaned from my experiences, was that making a child feel accepted was very important. Alan and I have raised two children; Bernard, who is 26 years old, hard-of-hearing, a graduate of Princeton University and Stephanie, age 21, deaf, and in her second year at Gallaudet University.

Our Son, Bernard, and Daughter, Stephanie

When Bernard was born, we suspected he might have some hearing loss because of the apparent hereditary deafness in Alan's family. At the age of five months, Bernard's hearing was tested and it was found to be normal. We were advised to bring him back when he was one year old. We didn't heed this advise because Bernard appeared to be communicatively functioning well. However, we later learned that our son had mastered lipreading.

When Bernard was three years old, we noticed that he was not relating well with his peers in our neighborhood. We enrolled him in a pre-nursery program in hopes that this would help him develop social skills. After a short time, his teacher reported that he was not playing with his classmates nor was he talking to anyone in the school. She suggested that he get his hearing tested. Naturally, we were offended, but we decided to follow through with her suggestion.

Bernard had his hearing tested at the National Technical Institute for the Deaf. We were shocked to learn that he had at least a moderate to severe hearing loss. The audiologist advised us to verify his findings by going to another audiologist in the office of an otolaryngologist. We took him to one and believe me, it was one of the most traumatic experiences of our lives.

During the visit, an audiologist took Bernard to his office while we waited in the waiting room. Approximately 15 minutes later, the audiologist came back dragging Bernard who was crying. He told us that he could do nothing with Bernard as he was not cooperative during the test. He told us to bring him back when he was good and ready. We were furious at the way he had handled our son and demanded that he do the test again

in our presence and with our assistance. At first he was hesitant to comply with our request but we were persistent with our demand.

In the testing room, the audiologist handed Bernard an abacus with colored beads for him to move from one side to the other each time he heard a sound. There was no communication or explanation on the part of the audiologist to Bernard and it was clear that Bernard was tentative and frightened with not knowing what was expected of him. As tactfully as possible, Alan asked if he could participate in the session and the audiologist agreed. With approximately 20-25 pennies, Alan, in a fatherly way, asked Bernard to play a game with him. Alan challenged Bernard to take a penny each time Bernard heard a sound through the earphones. Bernard cooperated and enjoyed this "game". The audiologist was fascinated with Bernard's behavior and cooperation and he was then able to complete the test without difficulty.

The results were comparable to the earlier findings at NTID. Bernard had a significant hearing loss. The otolaryngologist told us that Bernard had "inner ear deafness". We asked for further explanation about the nature of the deafness and what recourse, if any, we had. He told us that he couldn't explain any more about it and at that point a hearing aid dealer came into the office to talk with the otolaryngologist. After the hearing aid dealer left, the otolaryngologist told us he had to leave for lunch. We were dumfounded at his rudeness in leaving us hanging and demanded time to speak to him. We proceeded to ask him what we should do to help Bernard and he simply told us to go to a Hearing and Speech Clinic, then he left the office.

We left the office in a daze. We couldn't believe what had just transpired that morning. Finally, we said to each other, "So this must be what other parents go through when they first discover that their child is deaf." This experience was a clear indication that

too many professionals were improperly trained or prepared to handle situations such as this one.

We took immediate steps to have Bernard fitted with hearing aids and helped his school teacher become more aware of the needs of a hearing-impaired child. In time, and after much work and support from us and his teacher, Bernard made steady improvement in his social relationships. We also sought professional advice from a social worker and a psychologist to help Bernard make certain social adjustments in the classroom. We made sure that his teachers in subsequent years were fully aware of his hearing capabilities and of his special needs in the classroom.

For a short period of time, when Bernard attended private kindergarten, he had completely stopped communicating with everyone, except us. This went on for several months and we became very concerned. We took him to a psychologist who succeeded in getting him to communicate with someone other than his family. The psychologist informed us that Bernard's unwillingness to communicate was wrought from fear–he feared that he would lose his hearing. We suspect that Bernard began to think this after the arrival of his adopted sister, Stephanie, arrived from Boston. We adopted Stephanie when she was 16 months old and knew at the time of adoption, that she was profoundly deaf. Bernard, of course, had wanted a little brother, but was initially happy when Stephanie joined our family. With the new addition to our family, we knew that Bernard would need some special attention. We tried to make the transition of being an only child to having a sibling an easy one, however, it was not an easy task. Bernard began to withdraw and kept mainly to himself. We even invited the neighborhood kids over for a party so that he could interact with his friends. We tried our best to make the adjustment easy for Bernard so that he would not feel rejected.

Stephanie had been the quietest of the 99 babies her foster mother had previously taken care of and so she suggested that Stephanie go through a series of tests. Stephanie was diagnosed as deaf at the age of four months and was fitted with hearing aids. Despite the outcome, the adoption agency decided to let Stephanie's foster mother keep her longer – just to make sure that she did not have any other complications. At age 15 months, Stephanie was officially put up for adoption.

Stephanie, at age 15 months, did not possess any language or communication skills. Even at sixteen months, she couldn't crawl to get to where she wanted to go. Because of our strong oral backgrounds, we decided that Stephanie would receive an oral education. We tried the oral approach with her for a couple of weeks but realized that she was not making any progress. This was probably the result of not have any prior stimulation of language. She did not comprehend nor did she respond to anything.

We realized that Stephanie needed more than just oral communication and so we began using Total Communication with her – using clear sign concepts with spoken words to facilitate her language acquisition and comprehension. Stephanie quickly became more responsive. She was always cheerful and happy when she learned new things. As she developed mastery of enough vocabulary to communicate her ideas and needs to us, we started to encourage her to use her voice to speak.

Stephanie was first placed in a Parent-Infant "Demonstration Home" program at the Rochester School for the Deaf (RSD) as soon as she joined our family. She continued at RSD for three years when we decided to transfer her to a self-contained classroom for hearing impaired children in the city of Rochester.

Stephanie had begun to display some negative behaviors which interfered with her learning her school work. We were fortunate to locate a child psychologist who had at least

intermediate skills in sign language and was able to communicate with her and with us. As therapy went on, she made some progress at school. Because the school's own psychologist was not trained to deal with deaf children, we demanded and won the right to bring in our own psychologist to sit in on meetings with us and school personnel. It was unfortunate that the psychologist moved out of state as it took us almost one year before we located a suitable replacement. In the interim, Stephanie continued to perform satisfactorily in school.

Stephanie made friends in our neighborhood faster and easier than Bernard when she was very young. Her friends were drawn to her vibrant and energetic spirit and they seemed to be fascinated with her. However, when she turned 9 or 10 years of age, those same kids gradually slid away from her as the communication became an apparent barrier. Being older meant less time playing and more time talking and for Stephanie, it was difficult to feel a part of the discussion.

We eventually made a decision to transfer her back to RSD. RSD afforded her the social and recreational activities for her overall growth and social development. Stephanie felt more at home with the kids at RSD; kids who were deaf, active and had similar communication styles. She had experienced a lot of rejection from the neighborhood kids but having us for parents, attending a school for the deaf and having a lot of deaf friends who were like herself, made up for it.

Stephanie's behavioral problems worsened at school and carried over into her life at home. We realized that Stephanie needed more help than we could give her and so she was placed in a residential treatment facility which had a collaborative program with RSD's education program. We're sure that she felt rejected by her family, but we tried our best to explain to her that we wanted her to get better and that we wanted her to grow up to

become a well-rounded young lady. When she completed the program, she emerged a well-adjusted young lady, still full of life and energetic.

Throughout her childhood, Stephanie was full of energy and enjoyed sports. She participated in YMCA activities with hearing children each weekend and also played Little League baseball with hearing kids. When she was older, she joined a women's softball team in the community and has played in regional and national tournaments. She was also very active in many youth leadership development camps, outdoor bound activities, and Space Camp.

Today, Bernard relies on a combination of lipreading and his residual hearing to communicate and comprehend what is spoken to him. The regular classroom proved successful for Bernard. The self-contained classroom program would not take him because he already possessed language that was more advanced that what they could teach. He was unable to attend the Rochester School for the Deaf because he did not satisfy the entry criteria for decibel loss, and a private school would not admit him because he was "too quiet." Despite the frustrations often felt when searching for the best educational and social match for child, we are very proud of his excellent academic accomplishments. Of course, academically, the potential was there for him to do much better; but like most other typical kids, he preferred playing Atari, working on his computer, listening to rock music, playing baseball, collecting baseball cards and reading.

Bernard graduated from Princeton University. He worked as a legislative assistant for a New York Senator for 3 years and is now in law school at the University of Buffalo.

Stephanie is beginning her second year at Gallaudet University and plays on the women's varsity softball team. Stephanie, still full of vim and vigor, has the ability to communicate in all forms of expression; American Sign Language, Signed English, speech,

and lipreading. We recently learned that Stephanie has Attention Deficiency with Hyperactivity Disorders through some testing that was done at Gallaudet University. She is now receiving proper services to help her with her academic studies. She is able to project "normal" behaviors and she can do her academics without feeling pressured.

In Closing

Now that we have talked about our personal experiences, we hope that you will realize that each of us (Alan's parents, Bernard, Stephanie, and of course, us) are unique individuals. It is important for parents and educators of deaf children to meet and interact with a diversity of deaf and hard-of hearing people and learn about their individual experiences. There is no way we can generalize or stereotype what a deaf person or a hard of hearing person should be like or should be doing. And, there are no simple rules to follow when parenting deaf children. The best advice we can give parents and educators of deaf children would be:

1. Treat your child as an individual.
2. Involve your child in everyday communication activities at home, school and in the community.
3. Provide your child with opportunities to be involved in enrichment activities with their peers, both hearing and deaf.
4. Expose your child to all kinds of experiences as you would with any other children, deaf or hearing.
5. Meet and interact with deaf adults in the community to learn more about their experiences, trails and tribulations.
6. Encourage your child to know their abilities and reach their potential.
7. Network with other parents of deaf and hard of hearing children.

8. Become involved in your child's school and advocate for their needs and for the needs of other children.

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